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Recommended Citation

Stuntzner, Susan and Hartley, Michael, "Resilience, Coping, & Disability: The Development of a Resilience Intervention" (2014). *Counseling Faculty Publications and Presentations*. 25.

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Article 44

Resilience, Coping, & Disability: The Development of a Resilience Intervention

Paper is based on a program presented at the 2014 American Counseling Association Conference, March 2014, Honolulu, HI.

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Abstract

Learning to live with a disability can be a significant transition, and many individuals struggle with the complex challenge of examining how the disability will affect who they are and what their role is in society. Counseling professionals can play a key role in helping individuals address common psychological and social barriers associated with disability. Focused specifically on promoting resilience among individuals with disabilities, the present article provides the rationale for the development of a resilience intervention for counseling professionals to define and better support how individuals transition to living with a disability. Implications address how counseling professionals can use the intervention to increase resilience among individuals who are struggling to adapt to disability.

Introduction

In the United States, one in five Americans has experienced disability (Brault, 2012). According to the Americans with Disabilities Act of 1990, disability is defined as a physical, sensory, or psychological impairment that limits major life activities, such as “caring for oneself, performing manual tasks, walking, seeing, hearing, breathing, learning, and working” (Maki & Tarvydas, 2012, p. 87). Learning to live with a disability can be a significant transition, and many individuals struggle with the complex challenge of examining how the disability will affect who they are and what their role is in society (Marini, Glover-Graf & Millington, 2012; Smart, 2009). Some individuals learn to cope with restrictions to major life activities within a relatively short amount of time, while

others require more time to adjust (Marini et al., 2012; Stuntzner, 2014; Stuntzner & Hartley, 2014). Coping with and adjustment to disability is an individualized process and two people with very similar disabilities are capable of very different outcomes and coping processes (Livneh, 1986). The high prevalence of disability challenges both individuals as they work to adapt to their disabilities, as well as helping professionals as we work to promote healthy responses to disability (Maki & Tarvydas, 2012). A resilience framework is one approach to assist individuals with disabilities and professionals working with them to cope with disability.

In an effort to help counselors understand resilience and its relevance to the needs of individuals with disabilities, the authors explain the (a) meaning of resilience and its associated factors, (b) potential application of resilience to the needs of individuals with disabilities, and (c) the rationale for a resilience intervention following the onset of disability. Following these sections, building upon the authors' previous scholarship and clinical experience, the authors present their resilience intervention, which integrates emerging research on resilience with information on healthy responses to disability to assist individuals to: (a) learn what resilience is, (b) identify personal barriers which may impede its development, (c) develop or enhance personal skills which can be applied and tailored to the various situations they experience, and (d) achieve a better quality of life. Once learned, each of the resilience practices taught in the intervention are applicable to the numerous situations encountered by persons with disability. Implications address how counseling professionals can use the intervention to increase resilience among individuals who are struggling to adapt to disability.

Defining Resilience

Emerging from the positive psychology movement (Seligman & Csikszentmihalyi, 2000), resilience is an asset-based approach that can help individuals respond successfully and creatively to their disabilities (Edhe, 2010; Hartley, 2010, 2011, 2013; McGeary, 2011; Miller, 2003; White, Driver, & Warren, 2008, 2010; Williams, Davey, & Klock-Powell, 2003). Masten, Best, and Garmezy (1990) define resilience as "the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances" (p. 426). One way to understand resilience is in relation to the classic stress-diathesis model, where "stress activates a diathesis, transforming the potential of predisposition into the presence of psychopathology" (Monroe & Simons, 1991, p. 406); however, from a resilience perspective, the stress-diathesis model fails to account for protective factors.

As an interactionalist framework, resilience is the complex interplay between an individual and his/her environment, in which the individual can influence a successful outcome by using internal and external protective factors, defined as the personal qualities or contexts that predict positive outcomes under high-risk conditions (Eageland, Carlson, & Sroufe, 1993; Luthar & Cicchetti, 2000; Richardson, 2002). Rather than a single trait or skill, resilience is understood to be the cumulative effect of multiple protective or resilience factors that allow an individual to be successful despite adversity, including "constitutional variables like temperament and personality, in addition to specific skills (e.g., active problem solving)" (Campbell-Sills, Cohan, & Stein, 2006, p. 586).

From a resilience perspective, what matters most are the relationships between intrapersonal resilience factors, such as locus of control, emotional self-regulation, spirituality, commitment, and interpersonal resilience factors, such as social and family support (Black & Lobo, 2008; Campbell-Sills et al., 2006; Farley, 2007; Hartley, 2010, 2013; Walsh, 1998). All of these factors work together with a cumulative effect (i.e., the more success from meeting challenges, the more resilience builds upon itself). It stands to reason that supporting resilience practices could benefit people who are struggling to adapt to the experience of disability.

Potential Application of Resilience to Individuals With Disabilities

Importantly, the problem is not adapting to biological conditions, but rather contesting dominant cultural perspectives that label and position people with disabilities as diseased, broken, and in need of fixing (Conyers, 2003; Hartley, 2012; Longmore & Umansky, 2001; Smart, 2009). While attitudes toward individuals with disabilities have improved, people with disabilities are often subject to less humane treatment than people who do not have disabilities (Longmore & Umansky, 2001). Since the early 20th century, eugenics has been used to explain disability as a biological difference in genetic heritage and innate ability (Block, Balcazar, & Keys, 2001). As a result, people with disabilities may encounter attitudinal, employment, learning, medical, societal, and environmental barriers – all of which have the ability to prevent them from participating in life to their fullest extent (Hartley, 2012; Hartley & Tarvydas, 2013; Smart, 2009). Thus, rather than biological conditions, it is social policies and practices that marginalize people with disabilities (Block et al., 2001; Hartley & Tarvydas, 2013; Smart, 2009), in essence, serving “to exaggerate disability and even construct disability” (Smart, 2004, p. 42). To be sure, social disadvantage is a result of both material barriers, such as high rates of unemployment, insufficient nutrition and poor living conditions, and lack of access to necessary medical and health supplies (Hartley & Tarvydas, 2013), as well as intangible barriers, such as dominant cultural messages of people with disabilities as diseased, broken, and in need of fixing (Hartley, 2012; Longmore & Umansky, 2001).

In response, resilience is a construct which has considerable applicability to the needs of individuals with disabilities (Hartley, 2010; Miller, 2003; White et al., 2008, 2010). Reasons for this are many and are related to the various changes people experience within themselves and with others following disability. Examples include the necessity of learning about, adapting to, and coping with their (a) disability; (b) changes in personal functioning; (c) negative thoughts and feelings as a part of the adaptation process; (d) societal and attitudinal barriers; (e) feelings associated with loss and disempowerment; (f) experiences of social injustice and discrimination; and (g) lack of access to services, housing, or meaningful employment (Marini et al., 2012; Smart, 2009). Because of these experiences, society expects individuals with disabilities to deal with and surpass much more than the presence of their disability. Yet, oftentimes, people do not receive the support needed to develop or enhance resilience practices.

Rationale for a Resilience Intervention

In line with the development of empirically-validated forgiveness and coping interventions for use among individuals with disabilities (Coyle & Enright, 1997; Enright, 2001; Hebl, & Enright, 1993; Kennedy & Duff, 2001; Kennedy, Duff, Evans, & Beedie, 2003; King & Kennedy, 1999; Lin, 2001; Stuntzner, 2008), as well as resilience interventions for use among college students (Steinhardt & Dolbier, 2008), there is a need to develop an empirically-validated resilience intervention to help individuals respond successfully and creatively to their disabilities. As part of a larger commitment to empowerment, the concept of resilience promotes the notion that individuals do not need to be defined by environmental problems, and there is no reason that these individuals cannot live healthy and successful lives. Similar to self-advocacy, resilience reinforces an underlying message that individuals do not need to be rescued and are not victims to their environments. The development and implementation of resilience interventions is one way to assist individuals who are struggling to adapt to the experience of disability.

While there is a wealth of research in support of resilience as an avenue to promote healthy responses to disability (Edhe, 2010; Hartley, 2010, 2011, 2013; McGeary, 2011; Miller, 2003; White et al., 2008, 2010; Williams et al., 2003), specific resilience techniques, approaches, and interventions have yet to be developed toward the specific needs and concerns of individuals with disabilities. Rather, the majority of the research focuses on the definition and clarification of resilience, potential barriers which may impede its development, and exploration of associated factors that are believed to develop or enhance resilience. While all of this research is important and warranted, there is a void related to the development and implementation of resilience interventions to help individuals with disabilities develop more skills, cope more effectively, and have an improved quality of life (Mackler, 1998; White et al., 2008; 2010).

Development of the Resilience Intervention

The authors' intervention is a 92-page training manual that provides step-by-step instructions for implementing the resilience intervention. Coverage of this intervention, in its entirety, is not possible; however, interested counseling professionals may contact the authors for additional information. Further, the following description of the intervention explains the underlying rationale and structure behind the intervention and will assist counseling professionals to help individuals address common psychological and social barriers associated with disability.

In developing the intervention, a review of the research found a relatively consistent list of factors associated with successful coping with the onset of disability. With an emphasis on a person-environment fit, the factors included intrapersonal resilience, such as: (a) positive emotions, hope, and the ability to tolerate stress (Farley, 2007; Mackler, 1998; Miller, 2003); (b) internal locus of control (Dunn & Brody, 2008); (c) tenacity and active problem solving (Neenan & Dryden, 2012; White et al., 2008); (d) spirituality and the belief that things will work out (Black & Lobo, 2008; Webb, 2003; White et al., 2008; Williams et al., 2003); as well as interpersonal resilience, such as (e) peer support (Black & Lobo, 2008; Neenan & Dryden, 2012); and (f) family support (Walsh, 1998; White et al., 2008). Based upon this research, the factors associated with

resilience were organized into a progression of ten modules beginning with intrapersonal factors, such as internal commitment and control, before moving toward interpersonal factors, such as positive peer and family support. Group facilitators (i.e., counselors, psychologists) are to present the modules in the order presented as this format allows professionals to introduce the concept of resilience and its overall relevance to the needs of persons with disabilities. The first module is most important because it introduces resilience as a concept, including the basic tenets that organize the rest of the modules. Additionally, the final module is intended as a time for review and reflection so that people are given the opportunity to reflect on what they have learned and how these skills apply to their current situation.

The modules are an amalgamation of self-directed reflection activities with group sharing in order to hear, more in-depth, other peoples' stories and to identify which skills they feel need additional practice. When presented as a group intervention, people have the opportunity to learn the material and to share their experiences with others. Having the ability to learn, share, and apply the information and techniques presented gives people the opportunity to hear what others living with a disability experience and to understand they are not alone. More specifically, group learning provides people with the opportunity to receive validation from their peers in ways that might not be available if this information was presented in a one-to-one manner. Without being able to hear one's own story alongside the stories of others, it is difficult to see the larger principles behind each resilience practice. The ten modules are as follows:

1. Resilience as a concept;
2. Positive attitude and outlook on life;
3. Internal commitment and control;
4. Self-regulation of thoughts and feelings;
5. Tenacity and active problem solving;
6. Spirituality and the belief things will work out;
7. Forgiveness and compassion of self and others;
8. Personal growth and transcendence;
9. Social and familial support;
10. Review of the skills learned.

The format for each module begins with a definition of key terms and concepts, followed by a series of self-assessment exercises, activities, and discussions that culminate in an action plan regarding how to use each of the resilience practices to achieve personal life goals.

Structure of the Modules

All of the modules begin by introducing the basic tenets of the resilience practice with particular emphasis on each resilience practice as an evolving process in which a person's ability to feel and demonstrate resilience *continually* or *sporadically* improves with conscious and mindful awareness and practice. Following an introduction to the main principles of each module, each of the modules includes self-reflection activities designed to promote discussion of past coping strategies as well as how to develop new strategies to address problems and barriers impacting important life domains and the

achievement of life goals. The following sections provide a description of the general format and flow of the modules.

Basic Tenets and Definitions

Similar to other processes and interventions (i.e., adjustment to disability, forgiveness), resilience is not a one-time process, but one that is repeated and refined. In other words, each resilience practice, once demonstrated, can be *refined* and *developed further in detail* and *competency* based on a person's individual needs, disability, situation, and willingness to further his or her personal growth. Thus, it is important that participants gain insight and awareness of how to apply each of the resilience practices so they evolve into a life-long pattern of flexible behavior. Thus, mindfulness is a key component to generating insights about what participants would like to work towards and set life goals that are personally meaningful. Thus, mindfulness and engaged self-reflection regarding how participants are living or could be living life with a disability, may be a challenge for some.

In addition to explaining the underlying concepts of each resilience practice, each module is careful to note that the experience of disability may or may not be traumatic depending on the social and environmental context in which an individual lives. Importantly, a biological condition on its own does not represent adversity or challenge, rather it is the social disadvantage associated with disability (Block et al., 2001; Hartley, 2012; Longmore & Umansky, 2001; Smart, 2009). As a result, the lived experience of disability can be uniquely beautiful and shaped by a person's particular social and cultural identity (Conyers, 2003; Snyder & Mitchell, 2006). However, without an effective transition regarding how to live with disability, the experience of disability is often ambiguous and confusing. Rather than defining a good life as the absence of adversity, the emphasis is people's ability to face and overcome it (Dunn & Brody, 2008).

Self-Reflection

An initial step to becoming mindful of habits depends on reflections of self. As such, each module includes activities to promote self-reflection to help participants understand their own ability to demonstrate resilience, real or perceived. For instance, in *Module 1*, participants are asked to respond to 16 true/false statements that tap into a person's thoughts, feelings, or behaviors when faced with challenging life events. As an illustration, one item asks participants to respond to the statement: "dealing with challenges makes me a stronger person." Following each participant's response and explanation as to why, group facilitators will want to ask participants to elaborate on their response, engaging participants in discussions of what is effective coping. For participants who do not believe that dealing with challenges makes them stronger, group facilitators will want to encourage or generate stories of other individuals with disabilities who have experienced similar difficulties and found ways to grow stronger. In contrast, for participants who believe that dealing with challenges makes them stronger, group facilitators will want to ask them to share what they learned about themselves and their abilities. People often discover they have more tenacity and resilience than previously thought. Validating the effectiveness of participants' past coping is an important component in assisting participants to transfer their ability to cope in the past with the

ability to cope in the future. The significance is that nobody wants to face adversity, but many people do a remarkable job of coping.

Life Contexts and Goals

Next, each module asks participants to re-examine which areas of life have been most affected by the presence of disability. The goal is for counseling professionals to engage participants in a dialogue of how to utilize the resilience practices in each of the modules to promote healthy responses to disability. Stepping away from the old assessment paradigm of “test-and-tell,” group facilitators will encourage participants to apply the insights gleaned from the self-assessment activities to particular life goals and lifestyle preferences, making the information useful to the participants in understanding the past and creating change in the future (Burlew & Morrison, 1996, p. 163). A starting place may be to explore the following general life areas, such as personal functioning, family relationships, employment, and recreation. As related to the concept of resilience, people may feel and act in positive and adaptive ways in some parts of their life while still being challenged to do the same in other areas. Group facilitators will want to encourage participants to be mindful of other areas of importance and encourage participants to explore these should they arise. Participants are encouraged to reflect and identify what “skills” they currently use or have used to help them cope and overcome difficult life events.

Barriers Between Attitudes and Actions

Resilience, by definition, is a path fraught with challenges, and each of the modules addresses barriers that may make it difficult to implement each of the resilience practices into everyday life. Thus, it is important for participants to explore and learn about potential barriers between their *attitude* and *actions*. For instance, when people perceive a situation as something which can’t be influenced, changed, or as negative, they are more likely to hold poor perceptions which can lead them to giving up and not even trying to help. With respect to disability, a biological condition is difficult to change; however, one’s approach to living with a disability is malleable and open to interpretation. In addition to attitudes, it is important to consider concrete barriers in the environment, which may make life change harder to implement. Barriers may contribute to people feeling hopeless or disengaged because they believe nothing they do will make a difference, so why even try? These are common feelings and ones that should not be ignored. As part of learning to implement resilience practices in everyday life, it is important that participants identify both material and intangible barriers that may make life change difficult. As a group, participants will brainstorm potential ways to mediate these barriers to allow an individual to improve his or her life.

Application of Skills to Life

At the conclusion of each module, it is important that participants have a solid understanding and awareness of how each of the resilience practices may be applied within their own lives. Without group discussion, it will be difficult for participants to transfer the skills learned in each module to enhance their present and future life. The effectiveness of the intervention is dependent on individual participants developing individualized repertoires of coping based on each person’s disability, personality,

history, culture, and aspirations with a focus on how participants overall endure lessons of disability as strategic resources to create personal meaning and strength (Neenan & Dryden, 2012; Snyder, 1998).

Future Directions and Implications

As a work in progress, the authors' resilience intervention is in the process of being pilot tested among individuals with a variety of types of disability. Projects are underway to pilot test in Centers of Independent Living as well as with veterans with spinal cord injuries transitioning to civilian life. The data from these studies will be used to refine each of the modules. The ultimate goal is to incorporate the intervention into hospital settings, such as spinal cord injury clinics, as well as in community and vocational support programs, with a particular emphasis on targeting individuals in the initial stages of learning to cope with disability. In line with effective rehabilitation, there is a need to address not only medical symptoms, but also help individuals respond successfully and creatively to their disabilities, ultimately improving vocational and independent living outcomes.

With this in mind, the present article serves to share the initial development and structure of this resilience intervention with the intent of encouraging counseling professionals to promote resilience among individuals who are struggling to adapt to disability. Ultimately, the authors hope that this article will motivate counseling professionals who work with disabilities to define and better support how individuals transition to living with a disability. Thus, counseling professionals interested in learning more about the entire intervention are encouraged to contact the authors. Of particular interest is feedback about the creative and ingenious ways counseling professionals are able to alter or tailor the information provided in the intervention. Finally, the authors hope that the present article provides hope and motivation for individuals who are struggling with disability to increase resilience and reduce psychological distress. Learning to live with a disability can be a significant transition, and many individuals struggle with the complex challenge of examining how the disability will affect who they are and what their role is in society. As such, resilience is critical.

Conclusion

There is a great deal of research supporting the utility of resilience as an approach to improving psychosocial adaptation to disability. As such, resilience is an important lens to address common psychological and social barriers associated with disability. Focused specifically on promoting resilience among individuals with disabilities, the present article described the motivation and rationale for the development of a resilience intervention that counseling professionals can use to increase resilience among individuals who are struggling to adapt to disability.

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Note: This paper is part of the annual VISTAS project sponsored by the American Counseling Association. Find more information on the project at: http://counselingoutfitters.com/vistas/VISTAS_Home.htm